

SIOF Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Care of Long-Term Survivors

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This is the third official document of the SIOF Working Committee on Psychosocial issues in pediatric oncology constituted in 1991. This document develops another topic already discussed and approved by the SIOF committee.

The topic: "Care of long-term survivors" is addressed to the pediatric oncology community as guidelines that could be followed for considering this issue in a more appropriate way.

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INTRODUCTION

We have entered a new era for children and young people with cancer. Great advances in treatment have created a large and growing population of young people who are successfully off treatment for this disease. In the past, psychosocial care for childhood cancer survivors was focused on preventing the psychopathology and adjustment problems that were expected outcomes of long periods of isolation, trauma, close and continuing association with death, and experimental treatment. Now we must be more concerned with maintaining and improving the psychological health of a much larger population. It has been estimated that by the year 2000, one in every 900 young adults will be a survivor of childhood cancer. This position paper describes a set of guidelines or standards for the appropriate care of long-term survivors avoiding the risk of using excessive medical resources. The goal is to promote long-term physical, psychosocial and socioeconomic health and productivity, not merely to maintain an absence of disease or dysfunction. We need a proactive and preventive set of "standards for care," ones that offer services for possible clinical problems and regular check-ups.

At the Time of Treatment Cessation

Programs oriented to the individual needs of each long-term survivor of childhood cancer must begin when the child or young adult goes off therapy. The physician, possibly with a nurse, should meet with the family (and with the patient, according to age) to review the past and plan the future. Also, the psychologist or social worker,

if one is available, could meet with the family. They may have expertise to address adjustment problems (for the child or family) that the physician may not be well-versed in. The local pediatrician as well as the family physician or health care provider could be involved for sharing the results with him/her. Many young survivors will go to their local pediatricians or community physicians for follow-up. It is essential that these persons are fully informed as to nature of the previous illness, treatment, toxicity, and future problems to attune the care to the patient's needs. It is important that the center offers a counselling service for serious medical and psychosocial problems. This must be translated into a program adapted to individ-

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ual needs and local cultures. Moreover, the child and parents, if appropriate, must be provided with a written short summary of his/her clinical story briefly reporting the received therapy and the associated toxicity. It is also very important that each center carefully preserve all the information about survivors from cancer through an information system so that these data could be available even after many years.

Establishing an Off-Treatment Clinic

We advocate the establishment of a specialty clinic oriented to the preventive medical and psychosocial care of long-term survivors. This clinic should preferably be managed by the pediatric oncologist who treated the child and should have available a full range of adult and young adult specialists as consulting physicians (e.g., cardiologist, gynecologist, internist, etc.). Personalized programs should monitor and address each long-term survivor for special conditions related to their unique history, as well as their normal developmental concerns. Programs should include psychological counselling for young people experiencing adjustment difficulties and physical rehabilitation programs for survivors with significant side effects such as bodily disfigurement, limb amputation, sight or hearing loss, cardiac damage from chemotherapy, central nervous system limitations from radiation treatment, sterility and cognitive deficits. In addition, information should be provided on the avoidance of health risks such as smoking, unprotected sex and sun exposure and on health promotion behaviours, such as a good diet, exercise, stress avoidance and social support. The vast majority of survivors and their families will be psychologically healthy, but nevertheless may desire and benefit from proactive and preventive care and linkage to community or self-help supports. A relatively small, but nevertheless important, portion of the survivor population will be sufficiently psychologically distressed by their experience to exhibit adjustment problems severe enough to warrant professional intervention and treatment.

Public Health and Education/Advocacy Efforts

Research indicates that survivors of childhood cancer and their families could face social and economic discrimination. Constraints have been documented in limited access to social and educational opportunities, employment discrimination and the unavailability (or high cost) of health and life insurance. Comprehensive programs for survivors must include public education and advocacy that: (a) informs and persuades the general public of the essential normality and productivity of this population; (b) helps create public policies to prevent or confront such discrimination; and (c) educates survivors to be advocates for their own social and economic futures.

Final Comment

We are facing a very new problem in medicine: long-term evaluation of an increasing population of patients treated as children for cancer and now considered cured. The long-term survivors and the families are entitled to be protected from possible damage from the public society based on their past history of cancer. The pediatricians who helped to cure these patients should be the ones who encourage and advocate the promotion of this "new dimension" of pediatric oncology following (and perhaps expanding) the here presented guidelines.

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